

## Conceptualizing the Patient in Medical Humanities: A Posthumanist Intervention

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Suddenly the cancer in me was the cancer that is everywhere. The cancer of cruelty, the cancer of greed, the cancer that gets inside people who live downstream from chemical plants, the cancer inside the lungs of coal miners. The cancer from the stress of not achieving enough, the cancer of buried trauma. The cancer that lives in caged chickens and oil-drenched fish. The cancer of carelessness. The cancer in fast-paced must-make-it-have-it-smoke-it-own-it formaldehydeasbestospesticideshairdyecigarettescellphonesnow. [...] Cancer, a disease of pathologically dividing cells, burned away the walls of my separateness and landed me in my body, just as the Congo landed me in the body of the world. (Ensler 7)

I begin this conference paper with a quote from Eve Ensler's recently published memoir *In the Body of the World* because it illuminates how Ensler's journey with uterine cancer allowed her a *return* to a body from which she had been exiled; woven into her narrative of illness are the inextricably linked stories of her own traumatic experiences with childhood sexual abuse and the stories of suffering she witnessed as a feminist activist in the Congo. While claiming to be "no apologist for cancer," Ensler credits the bodily trauma of the disease for providing an access point through which to see herself as embedded within a body that is connected to a world.

I will return shortly to Ensler's eloquent and inspiring account of her experience but, for now, I will suggest that the memoir's relevance to this paper lies in its decidedly posthumanist perspective on what it means to be human in and through the embodied experience of disease—a perspective that views vulnerability and fragmentation as central experiences that connect us to one another and to nonhuman animals. After providing a brief overview of the humanistic impetus of medical humanities, I will introduce the phenomenological concept of posthumanism and explain its relevance within a contemporary medical sphere that seems intent on reforming its relationship to the human. This posthumanist intervention calls upon medical humanities scholars, medical practitioners, and medical students to think more critically about the rhetorics of holism, autonomy, and humanization endemic within current attempts to reconceptualize the

patient. Specifically, I hope to explore how consideration of the body's incomplete, atomistic, and fragmentary nature poses an occasion for a doctor-patient relationship founded on what Cary Wolfe and others identify as the shared vulnerability of human existence.

### **Medical humanities: a brief overview**

Returning to one of the probing questions of Ensler's memoir—that is, what it means to be human in and through the embodied experience of disease—we are faced with a line of inquiry that sits at the forefront of ongoing conceptual renegotiation within the medical field. Beginning most notably, perhaps, with the work of French poststructuralist Michel Foucault, modern medicine has been heavily criticized for its objectification of the patient and its reductive, atomizing view of the individual as merely a diseased body or medical case (Foucault 168).

In the midst of the debate over paternalism and autonomy, objectification and empowerment, the concept of medical humanities began to emerge in the United States between 1960 and 1970 (Brody 1). In 1977, the Committee on Humanizing Healthcare, established by the American Sociological Association, “defined ‘humanized healthcare’ as ‘care that enhances the dignity and autonomy of patient and health care professional alike,’ through treating patients as unique, whole, and autonomous persons” (Mishler 436). Since then, professional and scholarly voices have coalesced to articulate a predominant desire for medicine to move away from the current accepted system, in which patients are merely cases, to a mode of engagement that implements this humanized brand of healthcare (Brody 2, Polianski and Fangerau 121, Shapiro et. al 192-3, Macnaughton 928). Prioritizing empathy and compassion as necessary facets of the doctor-patient relationship, much of the scholarship in this area revolves around teaching

physicians-in-training how to be more ‘humane’ doctors—that is, more caring, more observant, and more invested than their forbearers, the alleged “demigods in white” (Shorter 794).

A literature review of the scholarship on medical humanities—whether endorsing, justifying, or criticizing its inclusion in medical curricula—reveals that articles on the topic frequently begin with the premise I have just described; that is, a narrative of contemporary medicine that places the patient in an objectified, dehumanized, and powerless position. M. G. Kidd and J. T. H. Connor, for one, worry that “without a humanist perspective, a patient might easily be represented—and treated—atomistically, as no more than a collection of organs and systems” (46). Along the same lines, Alan Petersen et al. note that in North America and the UK, “the medical humanities are conventionally seen to redress a *deficit* in medicine” (2). This deficit, observes Jill Gordon results from the “relentless reductionism of the biomedical sciences. [...] History, philosophy, and sociology,” she notes, “warn that the person with the disease is all too easily reduced to the non-hygienic, non-rational, disordered ‘other’” (5).

Following from these observations, medical humanities professor Jane Macnaughton suggests that the movement is—or should be—focused on systemic change. The medical humanities field emerged “as a result of a growing sense that there was something inadequate about medicine’s understanding of the human” (927). Macnaughton argues that despite challenging “depersonalization and molecular reductionism,” medical humanities have not sufficiently infiltrated medical teaching or practice to achieve a more productive conceptual model of the human (930). The reimagination and rehabilitation of the conception of the patient, these scholars note, must begin with a more robust, holistic understanding of the individual that extends beyond the physical markers of disease to account for the ‘whole person,’ an entity

composed of idiosyncratic biological, genetic, emotional, psychological, social, and cultural aspects, and possessing highly subjective experiences of disease.

McGill University medical faculty Helen Mc Namara and J. Donald Boudreau observe that this ‘whole person care’ requires skills generally fostered by a humanities education, and can be taught by imparting such tools as narrative analysis, communication skills, cultural competency, self-reflection and creative writing, and ethics-based reasoning. In this model, “healing involves reconciliation of the meaning(s) an individual ascribes to distressing events within his or her perception of personal integrity and ‘wholeness.’ This suggests that suffering may be associated with ‘disrupted wholeness’” (Mc Namara and Boudreau 191). Similarly, Moira Stewart, professor of family medicine at the University of Western Ontario, Canada, highlights the role of doctors in “help[ing] patients put the fragments of their lives back together into a whole” (793). Also promoting this ideal in his discussion of narrative medicine and patient subjectivity, sociologist Arthur Frank suggests that the restitution of narrative wholeness can lead to ‘humanization’; while patients’ “chaos stories are antinarratives in that they are told from within *dehumanized* time—time without order and thus without meaning,” the act of narrating an experience “humanizes the chaos of what has happened to [the patient]” (213).

The implication in each of these scholars’ work is that chaos or fragmentation—arguably rather unavoidable human experiences—are introduced into individuals’ lives through illness and that this experience is essentially dehumanizing. This notion evidently works toward an agenda within medicine to contain deviance within a manageable framework and to assert control over outliers, rather than to allow that death and vulnerability are oftentimes beyond medical control. Modeling humane medicine to future doctors thus means passing on liberal humanist ideals like wholeness, integrity, and agency, as key defining traits of the ‘fully human’ person.

## **A posthumanist intervention**

Returning to the 1977 statement made by the Committee on Humanizing Healthcare that defined its goal as promoting care that “[treats] patients as unique, whole, and autonomous persons,” we are left with the question: why are autonomy and wholeness, specifically, equated with humanization? (Mishler 436).

Examining the philosophical leanings of liberal humanism, we find an arguably quite admirable value system, one which evolved from Enlightenment thinking that sought to affirm the dignity and worth of each individual. Understandably, then, the impetus to reaffirm liberal humanist interpretations of the person within healthcare extends from an equally positive aspiration to promote compassionate and empathetic engagement. Problematically though, upon closer examination, we see that humanistic “aspirations are undercut,” as critical theorist Cary Wolfe notes, “by the philosophical and ethical frameworks used to conceptualize them” (xvi). Indeed, through the assertion of allegedly ‘universal’ human qualities such as rationality and self-determination, humanism sets out rather narrow expectations for human behaviour. Indeed, the same thinking that idealizes completeness, holism, and autonomy also produces the very conceptualization that medical humanities says must be reimaged—that is, what Wolfe identifies as the “fetishization of agency” and a view of the diseased body as something that can be taken apart and put back together (138). As disability studies scholars note, this “liberal humanis[t] preoccupation with autonomy and agency as conditions of human status and civic participation” excludes from the category of ‘human’ any body that fails to meet these criteria (Wolfe 138). Indeed, while medicine seeks to reestablish “the body’s previous and privileged ‘wholeness’” some bodies never will be—or never have been—‘whole,’ in this sense, whether due to amputation, paralysis, cognitive impairment, developmental disability, psychological

disorder, or any other ‘abnormal’ bodily state (Sobchack 22). As I will explain shortly, we can push this idea further to posit that no body—whether ‘normal’ or ‘abnormal’—can or should be labeled ‘whole.’

Following from these contradictions, I argue that the antithesis of this so-called ‘whole person’ model—that is, an atomistic view of human nature—does not necessarily preclude or undermine the positive goals of medical humanities, particularly if it focuses on the shared vulnerability that is engendered through the very condition of incompleteness or fragmentation. This is not to say that the patient *should* be viewed, in the words of Kidd and Connor, as “no more than a collection of organs and systems” (46); indeed, as many scholars before me have noted, this narrow biomedical view of human functioning is far from productive. Instead, posthumanist theory can allow for the construction of a more nuanced model of the human being within medicine that deprioritizes goals of heteronormative compliance and instead imagines the body as *never* complete, particularly not in and of itself.

To narrow in, briefly, on the potential value of medical posthumanism, we must first and foremost ask the very question posed in the title of Wolfe’s text *What is Posthumanism?* (2010). Acknowledging that posthumanism continues to be a highly contested term, Wolfe distinguishes between the terms *posthuman* and *posthumanist*. The posthuman can be defined as that which comes *after* human embodiment has been transcended and the “ideals of human perfectibility, rationality, and agency inherited from Renaissance humanism and the Enlightenment” have been taken to their utmost extreme (what we may refer to as transhumanism) (xiii). This is not the line of thinking that Wolfe wishes to develop. Instead, he formulates a notion of posthumanist theory as a *critique* of humanism, particularly its “fantasies of disembodiment and autonomy” (xvi). For the purposes of this paper, posthumanism signifies: 1) “a historical moment in which the

decentering of the human by its imbrication in technical, medical, informatic, and economic networks is increasingly impossible to ignore” (xvi); and 2) an acknowledgment and acceptance of human materiality, embodiment, and mortality from which liberal humanism has striven to escape. (As an aside, Wolfe also notes that in order to be truly posthumanist, posthumanist thinking must deconstruct itself, in order to avoid reinscribing the hegemonic discourse and practice it rejects. However, I will focus here on what Wolfe’s thinking means, specifically, for medicine’s conception of the human...)

In contrast to the institutional imperatives of technocratic medicine that reinforce binaries and highlight the uniqueness of the diseased body as individuated through medical need, Wolfe’s posthumanism seeks to topple binary oppositions between nature and culture in order to reveal our inextricable and “constitutive prostheticity” (xxvi). This theoretical turn asks us to recontextualize the human in terms of how our entire sensorium is necessarily dependent upon and coextensive with our technical and social environments—how our bodies and minds have evolved alongside our technical implements in a process of epiphylogenesis in a way that makes us *always already* decentered beings (Stiegler 175).

Semantics notwithstanding, at first glance, the ‘humanization’ movement within healthcare is entirely compatible with the posthumanist perspective in the sense that it, too, rejects the Cartesian mind-body split perpetuated by the medical model. The contradiction in terms within the discourse on medical humanities has emerged, however, through writers’, scholars’, medical doctors’, and other commentators’ demonstrable fixation on reorienting medical practice to focus on both autonomy and the ‘whole person’; indeed, endorsing the autonomy and holism of the patient as the key to rejecting illusory boundaries between our bodies and our environments is both problematic and counterproductive.

As Wolfe reminds us, the whole, autonomous human has never existed, despite the best efforts of liberal humanism to reject our vulnerability and other more ‘animalistic’ qualities. Although time constraints prohibit a more thorough exposition, posthumanism affirms these qualities, largely by pointing to the human being’s ‘radically ahuman technicity,’ expressed through the co-constitutive nature of our psychic and social systems. This co-constitution is most evident through “our subjection to a technicity of a language that is always on the scene before we are, as a precondition of our subjectivity” (Wolfe 89). Both our dependency on that which is ‘external,’ language, for one, along with our inescapable mortality are, together, what Wolfe, through Jacques Derrida, calls our “double finitude” (88). Central to Wolfe’s posthumanism, this double finitude is the shared condition that unites humans with other forms of life.

Within the medical sphere, both of these facets of human finitude are adamantly contested through what Jeffrey Bishop calls “a dream as old as humanity itself—to defer death” (17). To this I would add medicine’s equally powerful dream to deny the inescapable co-dependency and vulnerability that bring that mortality into awareness. Whether or not medicine can practically conceive of the paradoxes of death—for one, that the threat of loss also creates value, meaning, and connection—there is certainly much to be gained by practitioners in adopting a posthumanist perspective that destabilizes the foundations of hegemonic power structures (Bishop 3). “In the wake of this ‘after’ [of the posthumanist],” Wolfe suggests, “new lines of empathy, affinity, and respect between different forms of life, both human and nonhuman, may be realized in ways not accountable, either philosophically or ethically, by the basic coordinates of liberal humanism” (127-28). This perspective is central to conversations in animal studies, disability studies, and, to my mind, medical humanities—all areas in which hegemonic discourses of normalcy and difference result in the marginalization of particular



experiences and voices. For the medical field, especially, the opening up of “new lines of empathy, affinity, and respect” is particularly pertinent, considering expressed criticism within the literature over a perceived lack of empathy in healthcare practitioners’ encounters with patients (Warmington 328).

Speaking directly to the context of doctor-patient relationships, philosopher Ignaas Devisch, argues that the predominant focus within medical literature on patient autonomy unproductively dismisses the potentially positive outcomes of heteronomy—and, more to the point, incorrectly assumes that it can be avoided outright (43). “Under no circumstances,” claims Devisch, “I am always my own (autos) legislator (nomos). From the outset, all of us are exposed to heteronomy and maintain our lives by way of heteronomous means, whether through antibiotics for a simple flu, a blood transfusion or a variety of other operations, not to mention our genetic inheritance” (43). While Devisch notes that the appeal for care can be seen as, intrinsically, a relinquishing of total autonomy, I would suggest that not only when we become patients, but at all times, we are in unavoidable ways heteronomous. This is not to reject our abilities to act and think independently, but to dethrone autonomy as an ideal state of being. Certainly, as Devisch notes, “heteronomy is far more than paternalism or control; it can also mean transfer, trust, helplessness, shared responsibility, belief, et cetera. [...] Heteronomy is a condition of our autonomy, not an obstacle or something opposed to it” (43).

## **Conclusion**

In addressing the problematic rhetoric of patient holism and autonomy central to many definitions of medical humanities, I have also attempted to open up new avenues for understanding the roles of medical practitioners and healthcare seekers. I have not sought to

reject the laudable impetus of medical humanism toward promoting a degree of decision-making autonomy and freedom from paternalism for patients, which I agree should strongly guide the contemporary practitioner-patient relationship. However, the healthcare practitioner's focus must shift from maintenance or restoration of an illusory wholeness or completeness within the patient, to consideration of the philosophical implications of the human as always already incomplete, externalized, fragmentary, and coextensive with his or her environment. Disease does not mark a rupture in an individual's wholeness and integrity; the vulnerability and 'rupture' are present, in each of us—patient and practitioner, alike—from the start.

Devisch's notion of heteronomy, implicit in the work of Wolfe, is also central to Ensler's *In the Body of the World*, from which I quoted at the start of my talk. To conclude this paper, I leave you with a series of questions from Ensler, which are more aptly *challenges* to the clean, categorical imperatives of medicine. After dealing with a painful post-surgical abscess following the removal of her uterus, ovaries, cervix, fallopian tubes, rectum, and sections of colon, Ensler recalls the lead-up to her eligibility for radiation and chemotherapy. Along with the guilt and blame imposed upon her by cold, detached physicians who cruelly remark upon her body's too-slow recovery—"I feel as if I have failed," she despairs—she also writes of the dismissal and judgment attached to something so dull and non-vital as data (70, 88). The brutality of having her body categorized within a particular stage of cancer—either IIIB or IVB, they tell her—reminds her of being placed in the 'stupid' group in fifth grade—5.2B, labeled one of "the wrong children, the fat, the pimply, the depressed, the painfully introverted, the ones with behavioural disorders, the broken and oily-haired girls, the aggressive, menacing boys" (86). The resonances between these experiences that each *imposed upon her a deficit*, prompt Ensler to ask:

What if our understanding of ourselves were based not on static labels or stages but on our actions and our ability and our willingness to transform ourselves? *What if we embraced the messy, evolving, surprising, out-of-control happening that is life and reckoned with its*

*proximity and relationship to death?* What if instead of being afraid of even talking about death, we saw our lives in some ways as preparation for it? [...] What if, rather than being cast out and defined by some terminal category, you were identified as someone in the middle of a transformation that could deepen your soul, open your heart, and all the while—even if and particularly when you were dying—you would be supported by and be part of a community? *And what if each of these things were what we were waiting for, moments of opening, of the deepening and the awakening of everyone around us?* What if this were the point of our being here rather than acquiring and competing and consuming and writing each other off as stage IV or 5.2B? (89, my emphasis)

Through Ensler's memoir, we see that her experience with cancer, while ravaging and excruciatingly painful, does not create a 'narrative rupture' in the negative sense; it opens her to a world of interconnectedness in which she begins to see her suffering—and her joy—as belonging to, with, and in the world.

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